

My Brother
By: Michele Hicks

In June of 1998, I got a call from the NYPD about my brother, Michael. The detective told me that they had picked up Michael at the Waldorf Astoria Hotel.

He was wandering around the nineteenth floor with a suitcase. When security approached him and asked him where he was going, he replied that he was there to meet President Clinton. They contacted the NYPD, and when they arrived he appeared extremely agitated, confused, and hostile. They concluded it was best to take him to Bellevue for examination.

When he arrived at Bellevue he told them he had had open-heart surgery at the White House. I flew back to NY and went straight to see him. They had sedated him and admitted him. He was drooling and shuffling and completely unable to carry on a conversation. The person I had known as my brother wasn't there anymore. He seemed to be gone. Michael was 26 years old and had never been diagnosed with a mental illness or medicated before. They determined he was a Type A schizophrenic, which explained a lot about the last couple of years.

Michael is one year younger than me. He was always a very sweet, shy and gentle child. It was apparent from a young age that he had developmental delays. He was diagnosed as mild mentally retarded, then neurologically and perceptually impaired and was placed in special education classes. As he progressed through his teens, he became more withdrawn and difficult to communicate with.

As a young adult we were able to place him in supportive housing in NYC.

He seemed to do ok there for a short while but then the problems started. The social workers from the independent-living program were calling constantly. They were having problems with Michael because he wouldn't cooperate. He would not keep his appointments, attend the day program, or maintain his apartment or himself. He had started isolating and not answering the phone or door.

The apartment condition was atrocious, and we ended up removing ten to twenty bags of garbage multiple times. Michael would explain that he couldn't keep his appointments because he couldn't go outside. People were following him and it was too busy during the day. Michael constantly talked about hanging out with Metallica. He was convinced he was their band manager. And on and on. The fantasies and paranoia were getting worse.

He was constantly calling 911 saying he was having a heart attack. Then he would be taken to an emergency room only to determine it was a panic attack. This all led up to his hospitalization at Bellevue and his diagnosis of schizophrenia. How did we not put it together earlier? He was clearly showing the signs. How did his family, the case workers and the psychiatrist all not get that he was suffering from a mental illness? How long had he been living with this? How long had he been suffering?

He was now twenty-six years old. But he also has anosognosia.

Neither my mother, nor myself were able to offer him a structured environment or supervise him or his meds properly. The only way to bump him to the front of the treatment line was for him to be in crisis. And even then, the hospital only kept him there for as long as he was in crisis.

Unfortunately, the system is set up backwards. In order to get any help you have to wait until things get really bad. For most people that can be very difficult and extremely dangerous.

Nine months after entering Bellevue Hospital, an opening became available for Michael. He seemed to stabilize on his meds (and was released to supportive housing?).

But within a few years he starts disappearing from his residence for longer and longer stretches. He always ended up in the emergency room, at which point they stabilize him and return him to his residence.

This pattern repeats itself many times. We encounter unfriendly caseworkers who use HIPAA laws to restrict our family from getting any information about Michael.

My brother is severely ill and sometimes during his delusions he thinks my mother and I are the bad guys. Michael tells the staff not to talk to us, so they won't tell us anything, especially about his meds or medical care. Research proves that people with mental illness usually do much better when the family is involved in their care. Their needs to be a change in the way HIPAA laws are applied in the cases of the mentally ill.

This treatment of the people with severe mental illness and their families must end now. We need to change the government policies that are preventing adequate treatment for people suffering and adequate support for the families trying to deal.

We have to fix this broken system.

Thank you.